**EDNA interview guide**

**Phase 3**

**Intro notes**

The interview guide consists of 5 sections. Each section begins with a key opening question or statement that will be asked at each interview, followed by several consistently worded follow-up questions that may or not be asked depending upon the information that has already been offered by the participant. Slightly different versions of this question schedule will be devised for each group (anonymous donors, known donors; repeat donors; egg –sharers; those who didn’t complete a cycle…)

We decided to keep the introduction open to allow participants to provide an unsolicited version of their reproductive story and to tell their experience as they want to. This will also function as a part of rapport building. Some participants will speak for longer than others here, we can return to what they say later and pick up points of interest in subsequent sections.

The next section includes interwoven questions about experiences and decision-making. Some participants will have donated more than once and may provide a narrative that includes information about different donation cycles. This section will provide data on donor recruitment, how egg donation is framed and understood, factors affecting decision- making and motivations to donate.

The section of the interview on ‘experience’ guides the participant through their experience of egg donation, giving them an opportunity to tell us their story in their terms. We will allow them to spontaneously bring up aspects of the donation process that are important to them and prompt them to fill in any gaps. We will ask women to focus on the first time they donated eggs, but accept that for those who have donated more than once, their accounts of each donation cycle might cross over. This will provide in-depth data on their experiences of how they ‘became a donor’ and what they think they were doing in ‘donating eggs’. Interwoven in accounts will be policy inferences around compensation, anonymity, donor welfare and support, screening, informed consent (and what they think they are giving consent to versus what clinics actually do with their eggs). Areas for improvement in practice can be identified.

The next section of the interview will focus on asking the participant how they feel about being an egg donor. It will provide data on how they see themselves (subjectivities), how they imagine others (other donors, recipients and donor conceived children) and how they understand the reproductive relationships they have entered in to. It will give insight into their views on a number of important policy issues including anonymity/ identifiablity of donors, contact between donors and donor- conceived children etc. and how these particular policy choices are experienced by egg providers.

Following this, we have included two elicitation techniques based on abstract reasoning. Elicitation techniques combined with Socratic questioning will be used to obtain data on values and principles *that are relevant for policy-related issues* and the reasoning behind this.

These are (1) an elicitation technique to explore the issues around “ownership” of eggs and commercialisation of egg provision (2) an elicitation technique to explore the meaning of donation.

**Phase 3 Interview Guide (FINAL v10)**

**Opening**

Hello, my name is x and first I would like to thank you for agreeing to meet with me today to talk about your experiences of egg donation. Before we start, it is important that we go through this information and consent form [go through consent form].

You can speak for as long as you like, but the interview today will likely last around 1hr- 1hr30. I’d like to ask you about your own experiences of egg donation as well as your views about egg donation more generally.

Before we start is there anything you would like to ask me or anything else you would like to know about the research? Please let me know if you need a break or to stop at any time etc.

**Introduction**

1. To start off, can you tell me in your own words, how you first came across the idea of becoming an egg donor?

Depending how much they have already said –

OK, that’s a really helpful, overview/introduction – if its OK with you what I’d like to do now is ask you some specific questions about your experience OR I’d like to go back and pick up on a few specific details. For egg sharers, explain that this next part of the interview focuses specifically on their experience of donating their eggs but that this may also overlap with their experience of their own treatment.

**Decision-making and motivations**

2. To start with, let’s talk about when you first heard about the possibility – where was that? what did you do/who did you contact?

3. Who did you talk to about the decision? (ie. friends, family partner, online forums)

4. Did you seek out or did you receive any information about donation? [clinic websites, NGDT, Altrui/agency, donor testimonials, did you get in touch with other egg donors etc] What was most helpful to you?

5. How did you feel about the possibility at this point? (excited, apprehensive etc)

6. What made you decide to donate your eggs (probe – help, money, past reproductive experiences etc).

7. Where did you decide to go to donate your eggs? Why did you decide that rather than somewhere else? [clinic, agency, broker, egg bank]

8. What expectations did you have before the process started? Where did these ideas come from? Did your experiences match your expectations?

**Experience**

**So now turning to your** **experience during the process and once you got to the clinic**

9. Talk me through the process. What happened when you first contacted the clinic [agency, egg bank]? How long did it take them to get back to you?

10. **If agency**: what happened at the **first appointment**? Who did you see?

11. What **information** were you asked to provide **to the agency** about yourself? How did you feel about that?

12. When you then arrived at **the clinic**, what happened? Who did you see?

13. What information were you required to give to the clinic? (i.e. health screening questions as well as information for a future child (e.g. Pen portrait UK only)

14. Did you have any **tests**? Did you know what these were for? How did you feel about these? Were you given the results?

15. Was there anything you would have liked to know but were not told or didn’t feel that you were able to ask about?

16. Were you offered **counselling** before you started? did you take it up, what topics were discussed (did you bring them up, or the counsellor?) Did you have any other counselling sessions during the donation? Was this face to face?

17. What about the **medications** you had to take, how did they make you feel? Did you understand what they were for? Did you experience any side effects? How were these managed?

18. What was the **egg retrieval** experience like? **Do you know how many eggs were retrieved and what happened to them?** Were there other procedures you needed to go through?

19*.* What were you told about what would happen to your eggs? **Were you told anything about who might receive your eggs? Do you know how many women received your eggs?** Were you able to contribute to these decisions? If no, would you have liked to?

20. What kinds of paperwork did you need to complete? Did you understand what this was for? Consent forms etc. (with whom – agency/clinic?)

21. What happened after your egg donation? Were you offered a follow – up appointment? How was this for you [in case of yes, and in case of no]? How long after donation were you followed up by the clinic/ would you liked to have/needed…?

**If agency, did you receive follow up support from the agency? What did this consist of?**

22. Do you feel that you needed **support** during the process? If so, did you get this? If so, who from? If not, why not? What about later on?

23. Who did you tell about the donation?

24. Who supported you through the process? [family, friends, organisations, **egg donor recipients**, agency, counsellors, other egg donors…)

25. If you had questions did you know who to ask?

26. If you needed to, could you complain? Did you? [If yes, what happened then?]

27. What was positive about the experience? and what was negative?

28. Was anything better than you expected? Worse than you expected?

**Compensation**

I’d like to talk a bit about **any money that you received (skip if egg sharer)**

29. Did you receive any money?

30. How much money did you receive?

31. Did you know in advance about this money?, When did you first become aware that you were going to get money for the donation?

32. How was the money paid to you? By whom (clinic/agency/ recipients)?

33. How do you feel about the money you received?

34. What did you do with it?

35. Was this an important factor in the decision to donate?

36. Would you have still gone ahead with the donation if there wasn’t any money involved?

37. Have you told anyone about the money you received? How did they react?

**For egg sharers:**

38. I’d like to talk about the treatment you received in return for donating your eggs and what this meant to you.

39. Did you know about the option of egg sharing before you started treatment?

40. What treatment were you offered for donating your eggs?

41. Was this an important factor in the decision to donate?

42. What did the option/availability of egg sharing mean to you?

43. How do you feel about this?

**IF THEY HAVE DONATED MORE THAN ONCE:**

(If appropriate - I see from the questionnaire you sent us that you donated more than once)

44. Can you tell me a bit about that decision?

45. How did the later experiences compare to the first cycle?

46. What made you do it again? (probe donating for same/different recipients)

47. Did your reasons for donating change?

**Feelings/reflections**

48. How do you feel about the donation now?

49. Have you thought about what happened to your eggs? Have you been in touch with the clinic to find out the outcome of your donation? Were you told anything about this by the clinic/agency?

50. Have you thought about the recipients? If anonymous at the point of donation: Who do you imagine they might be?

52. Anonymity/contact - probes for each country:

**In the UK, ID release donors:**

* How do you feel about being identifiable to any children born as a result of your donation one they turn 18?
* Did you write a pen portrait? What did you think about when writing it?
* Have you thought about having contact with children born from your donation?

Is this something you talk about with others in your life? E.g. partners, (future) children, family members?

Would you donate if it were anonymous?

**For known donors in UK and Belgium:**

* have you discussed issues of disclosure or contact with future children with the recipients?
* What kind of relationship do you have now with any children?
* How do you feel about this?
* Would you donate if it were anonymous?

**Anonymous donors in Spain and Belgium:**

* although your donation was made anonymously, would you have liked to have contact with these children one day?
* Would you donate if you could be identified?

53. How important has being a donor been in your life?

54. Would you do it again? Why/not?

55. Have you donated other types of bodily material e.g blood? Is this different? How?

56. What would you say to someone considering donating their eggs?

57. What do you think discourages/encourages people from/to donating their eggs?

58. What - if anything - would you change about the process?

**Closing.**

That is all my questions.

How did you find that?

Is there anything else you would like to add?

Or anything you thought I might ask and didn't?

Do you have any advice for us in our research project?

If you have any more questions about the research you can contact me [at the phone number, address and email address provided on the Participant Information Sheet]. We will keep adding to our research blog and website and put information about our preliminary findings and outputs there so you can find out about how the project is progressing. If you are interested, I can send you a final summary report as we near the end of the project too, this will be in around 2 years time (if yes, how would you like to me to contact you?). As we talked about before the interview, you have the right to withdraw from the study for 7 days after giving the interview, all you need to do is let me know that you’ve changed your mind and we can remove your details from the study with no questions asked.

Thank you for your time.